DOCUMENT RESUME

ED 276 162 EC 190 914

TITLE	Handi Helps, 1985
INSTITUTION	Colorado State Univ., Ft. Collins. Cooperative Extension Service.
PUB DATE	85
NOTE	14p.
PUB TYPE	Collected Works - Serials (022) -- Guides - Non-Classroom Use (055)
JOURNAL CIT	Handi Helps; Jan-Apr, Oct-Dec 1985
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Asthma; Clinical Diagnosis; *Diseases; Etiology; *Information Sources; Occupational Therapy; Sexual Abuse; *Special Health Problems; Therapy
IDENTIFIERS	Kidnapping; Muscular Dystrophy; Scoliosis

ABSTRACT

The six issues of Handi Helps presented here focus on specific issues of concern to the disabled, parents, and those working with the disabled. The two-page handi help fact sheets focus on the following topics: child sexual abuse prevention, asthma, scoliosis, the role of the occupational therapist, kidnapping, and muscular dystrophy. Each handi help provides basic information (such as cause, diagnosis, symptoms, and treatment (in the case of diseases), practical suggestions for readers, and additional resources (such as organizations, books, and films). (DB)

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Handi Helps

January 1985

EC190914

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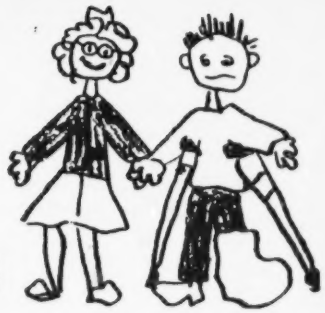

handi helps

January 1985

CHILD SEXUAL ABUSE PREVENTION

The U.S. Department of Health and Human Services has written a brochure on child sexual abuse prevention. This new publication provides numerous tips to parents and I would like to share them in this newsletter, with their permission.

Listen and Talk With Your Children

Perhaps the most critical child sexual prevention strategy for parents is good communication with your children. This is not only challenging to every parent but also can be difficult, especially for working parents and parents of adolescents.

- Talk to your child every day and make time to really listen and observe. Learn as many details as you can about your child's activities and feelings. Encourage him or her to share concerns and problems with you.

- Explain that his or her body belongs only to them alone and that he or she has the right to say no to anyone who might try to touch them.

- Tell your child that some adults may try to hurt children and make them do things the child doesn't feel comfortable doing. Often these grownups call what they're doing a secret between themselves and the child.

- Explain that some adults may even threaten children by saying that their parents may be hurt or killed if the child ever shares the secret. Emphasize that an adult who does something like this is doing something that is wrong.

- Tell your child that adults whom they know, trust and love or someone who might be in a position of authority (like a babysitter, an uncle, a teacher or even a policeman) might try to do something like this. Try not to scare your children--emphasize that the vast majority of grownups never do this and that most adults are deeply concerned about protecting children from harm.

Choosing a Preschool or Child Care Center

Although the vast majority of this nation's preschools and child care centers are perfectly safe places, recent reports of child abuse in these settings are a source of great concern to parents.

- Check to make sure that the program is reputable. State or local licensing agencies, child care information and referral services and other child care community agencies may be helpful sources of information. Find out whether there have been any past complaints.

- Find out as much as you can about the teachers and caregivers. Talk with other parents who have used the program.

- Learn about the school or center's hiring policies and practices. Ask how the organization recruits and selects staff. Find out whether they examine references, background checks and previous employment history before hiring decisions are made.

- Ask whether and how parents are involved during the day. Learn whether the center or school welcomes and supports participation. Be sensitive to the attitude and

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degree of openness about parental participation.

- Ensure that you have the right to drop in and visit the program at any time.

- Make sure you are informed about every planned outing. Never give the organization blanket permission to take your child off the premises.

- Prohibit in writing the release of your child to anyone without your explicit authorization. Make sure that the program knows who will pick up your child on any given day.

<u>If You Think That Your Child Has Been Abused...</u>

- Believe the child. Children rarely lie about sexual abuse.

- Commend the child for telling you about the experience.

- Convey your support for the child. A child's greatest fear is that he or she is at fault and responsible for the incident. Alleviating this self-blame is of paramount importance.

- Temper your own reaction, recognizing that your perspective and acceptance are critical signals to the child. Your greatest challenge may be to not convey your own horror about the abuse.

- Do not go to the school or program to talk about your concern. Instead, report the suspected molestation to a social services agency or the police.

- Find a specialized agency that evaluates sexual abuse victims--a hospital or a child welfare agency or a community mental health therapy group. Keep asking until you find a group or an individual with appropriate expertise.

- Search for a physician with the experience and training to detect and recognize sexual abuse when you seek a special medical examination for your child. Community sexual abuse treatment programs, childrens' hospitals and medical societies may be sources for referrals.

- Talk with other parents to ascertain whether there are unusual behavior or physical symptoms in their children.

- Remember that taking action is critical because if nothing is done, other children will continue to be at risk. Child sexual abuse is a community interest and concern.

- Make sure that your child knows that if someone does something confusing to them, like touching or taking a naked picture or giving them gifts, that you want to be told about it. Reassure the child and explain that he or she will not be blamed for whatever an adult does with the child.

<u>Observe Physical and Behavioral Signs</u>

Children who may be too frightened to talk about sexual molestation may exhibit a variety of physical and behavioral signals. Any of several of these signs may be significant. Parents should assume responsibility for noticing such symptoms including:

- Extreme changes in behavior such as loss of appetite.

- Recurrent nightmares or disturbed sleep patterns and fear of the dark.

- Regression to more infantile behavior such as bedwetting, thumb sucking or excessive crying.

- Torn or stained underclothing.

- Vaginal or rectal bleeding, pain, itching, swollen genitals and vaginal discharge.

- Vaginal infections or venereal disease.

- Unusual interest in or knowledge of sexual matters, expressing affection in ways inappropriate for a child of that age.

- Fear of a person or an intense dislike at being left somewhere or with someone.

- Other behavioral signals such as aggressive or disruptive behavior, withdrawal, running away or delinquent behavior, failing in school.

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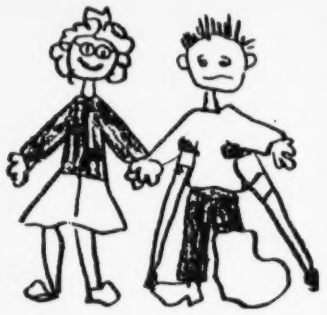

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February 1985

ASTHMA

Asthma is a chronic disease of the lungs which makes it difficult for the individual to breathe. One can breathe air into the lungs quite easily, but it is hard to get the air out. Trapped air is the real breathing problem.

Nine million people in the U.S. have asthma. They are people of all ages; it can begin at any age, in adults as well as children. People with asthma are from all walks of life and live in all kinds of climates and home environments. Medically, no two of them are exactly alike.

Of the nine million, the U.S. Public Health Service estimates that more than two million are children 16 years and younger. It is the most common chronic disease of childhood and the leading cause of school absences. One in 15 children will have at least one asthma episode and one in 40 will have repeated episodes or chronic disability.

The number of deaths from asthma has increased significantly in the past few years despite effective new drugs and therapies. More children died from asthma in 1980 than in any previous year. Overall the number of deaths increased by more than 10% in 27 states with increase of more than 80% in three states.

SYMPTOMS

People with asthma have bronchi and bronchioles that are much more sensitive and unstable than normal ones and become more irritated very easily.

Common symptoms include coughing, wheezing and a feeling of tightness in the chest. These characteristics occur because 1) the muscles wrapped around the airways, in the lungs, contract and narrow the diameter of the bronchis; 2) the linings of the airways become swollen and inflamed which further reduces bronchial diameter; and 3) bronchial glands produce excessive amounts of very sticky mucus which is difficult to cough out and which may form plugs in the bronchus. The result is an obstruction of the flow of air.

An attack can be brief or it can last for several days. A very severe, prolonged attack can threaten a person's life.

Asthma does not cause serious, permanent damage to the lungs or heart. Persistent severe asthma can lead to secondary health problems such as chronic fatigue if it is not properly controlled.

Additionally, the habitual use of shoulder and neck muscles for breathing may lead to the shoulders being carried up and forward, causing a round shouldered posture; chronic severe poorly-controlled asthma may have a slowing effect on growth; and because of considerable amounts of trapped air in the lungs, this may cause the chest to look large and over-inflated and resemble the "barrel-shaped" chest seen in emphysema. (Asthma and emphysema are two distinct diseases and do not appear related.) .

Psychological effects that may occur in children whose asthma is not well-controlled include: anger (Why me?); fear of dying; feelings of inferiority because of an inability to compete in strenuous activities and repeated absences from school; and feelings of being different and a burden, which can lead to depression.

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Asthma also affects the family unit. It can be a very expensive disease, it can limit the social life of parents because of the difficulty in finding babysitters, it can mean frequent trips to the doctor or hospital, siblings may resent what they see as special treatment, and it may act to magnify any number of other family problems.

CAUSES

Asthma is a complex problem that has baffled and challenged medical science for centuries. Many different things can trigger symptoms, for example:

Allergies. (Not all people with asthma are allergic and not all people who have allergies have asthma. The allergies can be from pets, foods, chemicals, common medicines e.g. aspirin, etc.

Exercise. (Exercise frequently leads to wheezing and coughing in people who have asthma. Each must learn their level of tolerance for physical activity and with this knowledge participate in exercise activities, as it is crucial to one's good health.

Infections. (Respiratory infections, colds, viral illness.)

Irritants. (Cigarette smoke, dust, strong odors, aerosol sprays, air pollution.)

Others. (Cold food or drink, hormones, menstrual periods, too much excitement, stress, anxiety.) It is important to note that asthma begins in the lungs, not in the head. No amount of stress or emotion will bring on an attack unless a person already has hyperreative airways.

The final answer may be an imbalance in one of the complicated biochemical systems involved in regulation of function of the lungs.

TREATMENT

There is no cure for asthma, but with careful diagnosis; expert medical treatment and conscientious self-care; good nutrition; plenty of fluids; adequate rest and exercise; prevention of infections; and avoidance of allergens, irritants and stress most asthmatics can lead normal, healthy lives.

A popular notion is that children can outgrow asthma. In some cases symptoms may decrease or disappear, perhaps because the airways get larger with normal growth, but the tendency toward asthma will always remain.

RESOURCES

National Jewish Hospital and Research Center/ National Asthma Center, 3800 East Colfax Ave., Denver, CO 80206 (800) 222-LUNG.

Parents of Asthmatic/Allergic Children (P.A.A.C.), c/o Nancy Sanker, 1412 Miramont, Fort Collins, CO 80524 (303) 482-7395. This group is designed to increase public awareness, provide education for both parents and professionals and offer emotional support for asthmatic and allergic children. They are interested in assisting teachers in mainstreaming children with asthma/allergies effectively into classrooms, providing pamphlets, answering questions and meeting with teachers/classes/others.

To assist with P.A.A.C.'s public awareness and educational objectives, this group is currently seeking $1,000 to purchase the "KIDS ON THE BLOCK" educational program on asthma. The program will be presented by CSU Extension Service and Colorado Department of Education's successful "MEET THE NEW KIDS ON THE BLOCK" troupe. If anyone is interested in helping with this project they can contact Nancy Sanker.

Thanks to the above resources for the information contained in this newsletter.

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March 1985

SCOLIOSIS

Scoliosis is an abnormal curvature of the spine. Everyone's spine has normal curves that produce a slight rounding of the shoulder area and an inward curve of the lower back, but in scoliosis the spine also curves sideways. It may resemble a letter "S" or a long letter "C". Another problem is that as the spine grows it gradually twists on its own axis.

Scoliosis generally appears between the ages of 10 and 15, when a child's spine is growing rapidly and it affects 5 to 10 percent of all adolescents to some degree.

Very mild scoliosis occurs at the same rate in both sexes, but adolescent girls are 7 to 9 times more likely to develop spinal curvature that requires treatment. The reason for this is not known.

CAUSES

Scoliosis can be the result of:

1. Functional causes, e.g. a result of poor posture or a discrepancy in leg lengths.

2. Structural causes, e.g. congenital defect or neurological disorders such as polio, spinal cord injuries, cerebral palsy or muscular dystrophy.

3. Idiopathic (causes are unknown). This is the most common form of scoliosis and appears in a previously straight spine, during the growing years.

A tendency toward scoliosis can be inherited and the disorder frequently runs in families. If one child is diagnosed, all the growing children in the family should be examined.

SIGNS AND SYMPTOMS

Symptoms usually don't occur until scoliosis is established. When symptoms do occur, they include: backache; fatigue; shortness of breath; subtle physical signs like one hip appearing higher than the other or more prominent; one shoulder blade being more prominent, with one shoulder higher than the other; from the back, the rib cage may appear to stick out or form a hump on one side of the spine (usually the right side); when the arms are hanging loosely at the sides, there may be more space between the arm and body on one side; repeated tilting of the head to one side; listing to one side. Other clues are uneven hems and waistbands, uneven bra straps or one pant leg hem riding higher than the other.

HOW TO DETECT

A parent can check their child for scoliosis by performing the following simple test. First have the child remove their shirt and stand up straight. Looking at the child's back answer the following questions: Is one shoulder higher than the other or is one shoulder blade more prominent? When the child's arms hang loosely at his/her sides, does one arm appear further from the body than the other? Is one hip higher or more prominent than the other? Does the child seem to tilt to one side?

Next ask your child to bend forward, from the waist, with arms handing down and palms together at knee level. Can you see a hump on the back at the ribs or near the waist? This position will make both sideways curve of the spine, plus any rib protrusions, more visible. It helps differentiate scoliosis from poor posture, which can be corrected

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merely by straightening up.

If your answer to any of these questions is "yes", notify your doctor. Your child needs careful evaluation for scoliosis. The physician will do a physical examination and take a series of spinal X-rays to make a definite diagnosis.

A recent FDA study ascertained that 18 states and the District of Columbia have mandatory school screening programs that generally cover grades 5 through 9. In addition, more than 20 of the remaining states have voluntary scoliosis screening programs at the state, county or local level. According to the American Academy of Orthopedic Surgeons, the "screening programs have dramatically reduced both the number and complexity of surgical procedures that are performed for scoliosis."

TREATMENT

To be most effective, treatment should begin early, when spinal curvature is still subtle. This provides the best chance of slowing or halting a progressive curvature.

The severity of the curvature and potential spine growth determine appropriate treatment. In most cases the curvature of the spine is so mild that the only treatment needed is close observation by a physician (spinal X-rays, physical examines every 3 months). Other forms of treatment may include exercises (sit-up pelvic tilts, hyperextension of the spine, pushups and breathing exercises to strengthen the torso muscles and prevent progression of the curve); a brace (halts progression in about 90% of patients, but doesn't reverse established curvature and is worn until bone growth is complete, usually 1 to 4 years); surgery (attachment of a thin stainless steel rod to straighten the spine and fusion--grafting small strips of bone over the affected vertebrae); or a combination of these.

A new technique uses an electrical muscle stimulator. This form of therapy became available in 1983. The electrical muscle stimulator causes muscles near the spine to contract several times a minute and provide a counteracting force against other muscles that are pulling the spine out of line. It is used only at night while the patient sleeps. It must be continued until the patient reaches bone maturity.

Untreated scoliosis may result in a restriction of the lungs, causing breathing problems and possibly heart disease in later years; back pain; degenerative arthritis of the spine; disk disease and sciatica.

HANDI HELPS (FOR THOSE WITH A BRACE)

1. Provide emotional support to help prevent depression that may result from altered body image and immobility.

2. Brace should be removed only for bathing and prescribed exercises. The brace should be worn 22-23 hours everyday as recommended by the attending physician.

3. Whild adjusting to the brace, the individual should lie down and rest several times a day.

4. Patient should increase activities gradually and avoid vigorous sports.

5. Individual should turn his/her whole body, instead of just their head, when looking to the side.

6. To make reading easier, books should be held so he/she can look straight ahead at it instead of down.

7. Cast should be kept clean and dry. Youth should not insert or let anything get under the case.

8. Cracks in the cast, pain, burning, skin break down, numbness or odor should be immediately reported.

CREDITS

Nurse's Reference Library, DISEASES, 1983.

FDA Consumer, September 1984.

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April 1985

OCCUPATIONAL THERAPISTS

This issue of HANDI HELPS deals with the important role an occupational therapist plays in the education of individuals with disabilities as related to their academic performance.

Public Law (PL) 94-142, The Education for All Handicapped Children Act of 1975, assures that all handicapped children will have available to them. . . a free and appropriate education which emphasizes special education and related services designed to meet their unique needs. Under this law, occupational therapy (OT) is specifically defined as a related service that works with children who have a handicap to enhance their learning potential.

Occupational therapists were originally employed in the school systems to work in special education settings to provide treatment to children with orthopedic disabilities. Therapists began applying their therapeutic philosophies and skills in the 1960's to work with children who have a broader scope of disabilities. By the 1970's OT became a recognized service in many programs designed to place more students in regular classrooms. Occupational therapists are currently members of educational teams working with elementary and secondary education staff and students. An educational team consists of local education personnel, teacher(s), parent/guardian, and when possible, the child.

To obtain the objectives of OT service programs, the therapist collaborates with others on the educational team and contributes to or participates in the development of an Individualized Education Program (IEP).

The IEP should include: statement of present level at which child is performing, annual goals including short term objectives, specific educational services provided and extent of participation, dates of initiation of service and duration, appropriate objective criteria, evaluative procedures and schedules. The IEP should provide the "least restrictive environment" for each student with special needs.

Five major roles of an occupational therapist within the educational setting have been adopted by the American Occupational Therapy Association, these include: evaluation, program planning, program delivery, consultation, management and supervision.

Evaluation

The first step in developing or implementing OT services is to identify those children who need the services. This is done through a screening process. Screening involves setting certain criteria for a particular population and identifying those children who do not meet the criteria and who therefore need further evaluation. Assessment may include:

--evaluation of need for adaptive equipment
--evaluation of gross motor development (walking, running)
--evaluation of fine motor development (grasp, object manipulation)
--evaluation of neuromuscular development (joint range of motion, oral reflex development, muscular strength and tone)
evaluation of sensory integration (equilibrium, sensory development)

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Program Planning

The occupational therapist, using the results of the OT evaluation, sets short-term and long-term goals to improve problem areas identified in the student's IEP.

Program Delivery

Program delivery is the implementation of an OT program designed to enhance the student's functioning and to enable the student to benefit from special education. Some examples of intervention are:
--to enhance fine and gross motor skills such as walking, running, writing, using scissors, etc.
--teaching activities to promote independence in activities of daily living such as transfers from wheelchair to bed, mobility, bathing, grooming, toileting, etc.

The occupational therapist can make a valuable contribution to the educational process by devising adaptive equipment needed by the child to function in the classroom. This includes equipment needed for seating or other positions in the classroom, as well as adaptive equipment for managing classroom materials, writing, eating, dressing and toileting. Some examples of adaptive equipment recommended or made by the occupational therapist are:
--different wheelchairs, depending on individual needs of the child
--wheelchair adaptations to aid normal body alignment, to neutralize primitive reflexes, to facilitate appropriate motor behavior and to provide comfort and security
--dressing aids such as button aids, sock aids and reachers
--feeding aids such as offset spoon and scoop dish to allow the child to feed him/herself.

Consultation

Another role identified for the occupational therapist in the school setting is to consult with school personnel and parents regarding OT for the child. The consulting role can be carried out on a one-to-one basis, in a formal in-service training for groups of parents or teachers or as a liason between the school system and community agencies. A summary of the areas of consultation follows:
--classroom or home environmental adaptations
--appropriate programs outside the school program
--special needs of the students
--preventative health education and activities to enhance the educational environment and learning potential of students

Administration and Management

The final role of the occupational therapist in a school-based program is managing and supervising the occupational therapy program.

In summary, occupational therapists work in educational settings such as public schools to enhance the learning potential for children with handicaps. They design and implement programs that will allow the children to benefit from their participation in special education programs. The most common reasons for referral to an occupational therapy program are: uncertain hand dominance, poor visual perception, problems with handwriting, inadequate ability to use scissors. The underlying reasons for these problems are assessed by the OT and then addressed in occupational therapy programs. Teachers are responsible for the majority of referrals to OT programs. If you are an educator and have children in your classroom who you believe might be possible candidates for OT, then contact the occupational therapist in your school district for further evaluation. If your school district doesn't have an OT, then contact the administrative office in your district for assistance.

The information in this issue of HANDI HELPS was compiled by Mona D. Oversteg, senior in OT at Colorado State University. Information was taken directly from the following sources:

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State of Iowa, Department of Public Instruction Physical Therapy and Occupational Therapy in the Iowa Area & Educational Agencies--Draft Guidelines

Stephans, L.C. (1985). In P.N. Clark and A.S. Allen, Occupational Therapy for Children, (pp. 471-488). St. Louis: The C.V. Mosby Company.

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OCTOBER 1985

KIDNAPPING

* 1.8 million children are reported missing each year
* 20,000 to 50,000 of the missing children are the victims of foul play
* 8,000 of these children are never found

I just finished reading a new book titled Kidnapping, Alerting Kids To The Danger Zones by Joy Berry. Even though the topic does not deal with a disability directly, as most issues of HANDI HELPS do, the consequences of a child being kidnapped can certainly cause emotional and psychological disabilities.

The information presented in the book seemed timely and invaluable for the target audience of this newsletter--elementary school staff/others who work with children. I hope some of the ideas/suggestions that follow will be useful for any discussions you may have with young children regarding this subject.

Hopefully the children will never be in a situation to use the information; however, their awareness of the problem and their knowledge of precautionary techniques can be their best protection. Additionally, children's imaginations can create worse than any actual situation. Children need correct and comprehensive information. During discussions with children on this topic, their questions need to be answered openly and honestly. The point of such discussions is to turn fear into healthy caution and to empower young people to remain safe, happy and free. Children should be reminded that most people in the world are good. However, there are a few who can be harmful.

Reasons Why People Kidnap Children:

* the desire for children because of loneliness
* the need for someone to do work for them
* the need for money
* the need to get back at someone because they are angry
* the need for someone to sexually abuse

Tricks Kidnappers Use To Get Children To Go With Them:

* bribes--promise children gifts
* tricks--tell convincing lies e.g. ask children to help them find a place because they are lost, tell them their mother was in an accident and they need to take them to her
* intimidation--tell children they are supposed to do what adults tell them
* force--use strength to overpower children

In Response To These "Tricks" Children Should:

* say no to anything a stranger asks them to do
* run away if a stranger tries to touch them

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* scream "Help I'm being kidnapped." if a stranger tries to grab them
* tell parents about any stranger who approaches them including type of car, what person looked like, etc.

Other Ways To Avoid Being Kidnapped:

* make sure your parents/guardians know exactly where you are and what you will be doing at all times
* avoid going places alone
* avoid being in deserted places
* avoid being in dark places
* if home alone, don't open the door for strangers or tell them you are alone

If Child Is Kidnapped They Should:

* try to find a trustworthy person and ask them to take them to the police
* try to get to a telephone and dial "0" and ask for the police; tell the police the number of the phone you are calling from and stay on the line until police locate you, if possible

Activities For Teachers/Parents And Children:

* have children practice calling the operator or dialing 911 for assistance
* teach children how to observe and describe people e.g. taller than Dad, lighter hair than Mom's, orange coat, etc.
* make a game of reading and remembering license plates including states they are from
* prepare children by role playing various "kidnapping scenes" with them
* encourage children to trust their intuition and react assertively when a situation does not "feel right" to them
* develop and have children practice filling out "location reports" before they leave the house--should include where they will be, what they will do, how they will get there and back home, etc.

Reminders For Parents:

* choose a secret code word to use with child in case of emergency--tell child never to go with anyone who does not know this code word
* don't put children's names on outside of their clothing or possessions--kidnappers can easily disarm children by using their name
* make a mental note of what children are wearing before they leave home
* make arrangements with school to be called if your children are absent
* parents should also put together an emergency information folder which might speed the work of police in locating child--should include: child's finger and palm prints from both hands, current photo (replaced every 6 months), lock of hair, race, height, weight, color of eyes, complexion color, identification marks, names/addresses/phone numbers of parents, relatives, close friends, neighbors

Information presented in this newsletter is taken directly from Joy Berry's book. The book is published by arrangement with Living Skills Press by the Educational Products Division of Word, Incorporated, 4800 W. Waco Drive, Waco, Texas 76796, 1984. Other Danger Zones books for children include:
Abuse and Neglect
Sexual Abuse

For additional information you can call, toll free, 1-800-382-0800--the National Child Watch Campaign.

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NOVEMBER/DECEMBER 1985

MUSCULAR DYSTROPHY (MD)

A healthy person moves through every day of his life using a self-powered system of more than 400 voluntary muscles that are attached to his/her skeleton. Movement occurs when bundles of muscle cells or fibers shorten in response to messages from the brain. This is how normal muscles work.

With MD muscle fibers deteriorate as a result of genetic imperfections that are usually passed on from parents. Muscle weakness and fiber damage are the common features of the various types of MD.

CLASSIFICATIONS

There are four main types of MD, all are a progressive degeneration of the muscles for which no cure has yet been found.

1. Duchenne or Pseudohypertrophic. This is the most common and most severe form of MD. It was first described by Duchenne, a French physician, in 1861 and currently affects about 10,000 male children in the United States. It is a sex-linked recessive disorder, which means that the defective gene is carried by a female and the disease is transmitted to a male.

Duchenne develops early, usually between the ages of 2 and 6. Symptoms may not appear until 50% of muscle tissue has been destroyed. Early signs to watch for are: a waddling gait, difficulty in rising from the floor or climbing stairs and a sway-back or protruding abdomen. These symptoms are due to weakness in large muscles of lower trunk and upper legs. It is sometimes called Pseudohypertrophic Dystrophy because fat and connective tissue sometimes replaces wasting muscle fibers, causing these muscles to falsely look overdeveloped. Although children with Duchenne MD might have mental retardation, many of them have normal intelligence. The disease progresses rapidly. Walking gets harder and a wheelchair is usually needed by adolescence. Soon all the muscles become involved. This often causes breathing problems and the patient may die within 10 to 15 years of when the disease began.

A test for the muscle enzyme levels in the blood, called a "CPK" test is used to find female carriers of Duchenne Dystrophy. Testing and genetic counseling is suggested for sisters and aunts of boys affected with this type of MD.

2. Facio-scapulo-humeral. The first muscles affected in this type of MD are the face, shoulder and upper arms. It usually becomes evident in the teens but could also occur in childhood or middle age. The severity of symptoms varies but they often begin with a decreased ability to move the facial muscles, followed by difficulty raising arms and lifting objects and also a forward slope of the shoulders.

Facio-scapulo-humeral MD usually progresses slowly, with long periods when symptoms do not get worse. Lifespan is rarely shortened. It can be transmitted by either parent to both sexes. There is usually a strong family history of the disease, with the defective gene appearing in nearly every generation.

3. Limb-girdle. Both parents must carry the defective gene for this type of MD to be transmitted. It can affect both boys and girls. It may simply result from

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a poorly formed gene rather than a defective gene in the family.

The onset of symptoms might come anywhere from late childhood to age 40. The patient might first notice weakness in either the shoulders or the lower trunk and upper legs. Weakness in the shoulders would cause problems in picking up objects. Waddling, frequent falls and difficulty climbing stairs are signs of weak pelvic muscles. The progression of this disease is unpredictable. Disability may be only slight, allowing the person an almost normal life; or it may be severe and rapid, in this case, the person may be unable to walk by middle age and the lifespan is usually shortened.

4. Myotonic. Appearing in early adulthood, the first symptoms are weakness of fingers, hands, forearms, feet and lower legs. Hands and feet may be especially stiff and the patient might have a hard time relaxing his/her grip on an object. In addition to this, he/she might have droopy eyelids and jaw due to facial muscle weakness and may trip and fall often. Walking becomes difficult as weakening spreads steadily and severe disability usually results in 15 to 20 years. The person's life might be shortened. Myotonic MD is transmitted by either parent to both sexes.

5. Other types. In Congenital Dystrophy, muscles are small and weak at birth and lifespan of the infant is short. Opthalmoplegic Dystrophy usually appears in adulthood and affects the eyes and throat. It progresses slowly but steadily. There is also a Late Onset MD that shows up when a person is in his/her 40's or 50's.

TREATMENT

For almost all of the muscular dystrophies, there is no treatment that halts the disease process. Physical therapy may delay wasting away of muscles or reduce the effects of the process. Occupational therapy will help a person to function at the maximum of his/her capacity through the use of assistive equipment and adaptive methods. Orthopedic appliances may be prescribed by a physician, as well as medications to control illnesses that accompany MD. Much of the treatment will be focused on keeping the patient as mobile as possible, trying to prevent unnecessary deformity and encouraging the patient to be independent in his/her daily activities.

HANDI HELPS

- Early diagnosis is important because a person's capacity to function and life expectancy can be increased. It is also helpful so that parents and female relatives can have genetic counseling to see if they are carriers of the disease.

- Patients with MD will feel stronger on some days and weaker on others. Parents/teachers need to keep this in mind and be prepared to be flexible in their expectations.

- A child with Duchenne MD does not usually require more rest than the average child, so encourage a healthy balance of activity and rest. In fact, if he/she is kept in bed more than a day or so, he/she might experience a rapid increase in weakness.

- Children with MD may be especially susceptible to colds and other respiratory diseases. They should be treated promptly.

- No special diets have been found useful in the treatment of MD. However, patients should be encouraged to eat a well-balanced diet and avoid overeating. Obesity is often a problem for children in wheelchairs. Remember that if a child has a decreased energy level he/she must also decrease his/her caloric intake.

- Attitudes of those around a child with MD are important. The family and others need to be supportive and maintain reasonable expectations, yet avoid overprotecting.

RESOURCES

National Muscular Dystrophy Association, 810 7th Ave., New York, N.Y. 10011.

Muscular Dystrophy Assoc. Regional Office, 245 Columbine, Denver, CO 80206.

The majority of the information in this issue of HANDI HELPS is from the MD Assoc. and was prepared by DeAnn Monsma, Senior, Occupational Therapy, Colorado State University.

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